CDC Cancer Registry Data Access for Research Project

Cancer Registry Research Approval Process:
Classification of States by Level of Approval Required

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National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Definition of Terms

1. **Approval process** - The approval process for research requests for access to confidential data is specific to each state cancer registry. The approval process may require cancer registry, institutional review board (IRB) and/or regulatory group approvals.

2. **Levels of approval** - The levels of review for approval range from one to four or more levels of review that may include the cancer registry, affiliated IRB, and affiliated regulatory groups.

3. **Sponsorship** - Clarifies if sponsorship from a local epidemiologist or state-based researcher is required for any research request to access confidential data.

4. **Committee** - This term represents any regulatory body or group, board, or review group different from the IRB, from whom approval is required.

5. **Epidemiologist** - This term represents a cancer registry-affiliated epidemiologist.

6. **Cancer registry IRB** - This term represents an institutional review board affiliated with the cancer registry.

7. **Level of complexity scale** - The level of complexity for gaining approval to access confidential data is based on factors including the number of levels of approval, timeframe for approval, pediatric special requirements, fees, sponsorship requirement, a limit on the number of studies allowed by the cancer registry or the IRB, and whether physician/patient authorization is required.

Cancer Registry Research Approval Process
Classification of States by Level of Approval Required

1. States that require one level of approval

State	One level of approval	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Alaska	Committee	Yes	No	Varies	No	No	No	Not applicable	Not Applicable	Not applicable	No	More
Arizona	Cancer registry IRB	No	No	Varies	No	No	Yes	Not applicable	Not Applicable	Physician	No	Middle
California	Cancer registry IRB	Yes	Yes	<2	No	No	Yes	Not applicable	Not Applicable	Patient	No	More
Colorado	Cancer registry IRB	No	No	2-6	No	Yes	Yes	Physician	Physician	Not applicable	No	More
Connecticut	Cancer registry IRB	No	No	<2	No	Yes	Yes	Not applicable	Not Applicable	Physician	No	Middle
District of Columbia	Cancer registry IRB	No	No	<2	No	No	Yes	Varies	Varies	Varies	No	Middle
Georgia	Cancer registry IRB	No	Yes	<2	Yes	No	Yes	Physician and patient	Physician and Patient	Not applicable	No	More
Idaho	Committee	Yes	Yes	<2	No	No	Yes	Physician and patient	Physician and Patient	Not applicable	No	More
Illinois	Cancer registry IRB	No	Yes	Varies	No	No	Yes	Patient	Not Applicable	Not applicable	No	Middle
Indiana	Committee	No	No	<2	No	No	Yes	Not applicable	Not Applicable	Physician	No	Less
Kentucky	Committee	No	Yes	<2	No	No	Yes	Patient	Not Applicable	Not applicable	No	Less
Mississippi	Committee	No	Yes	<2	No	No	Yes	Patient	Not Applicable	Not applicable	No	Less
Pennsylvania	Committee	No	Yes	<2	No	No	Yes	Not applicable	Not Applicable	Patient	No	Less
Wisconsin*	Not applicable	No	Yes	Varies	No	No	No	Not applicable	Not Applicable	Not applicable	No	More

*Wisconsin: Confidential data release policy under development. Currently, data linkage only.

Cancer Registry Research Approval Process
Classification of States by Level of Approval Required

2. States that require two levels of approval

State	Two levels of approval*	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Arkansas	• Epidemiologist • Committee	No	No	<2	No	No	Yes	Patient	Not Applicable	Not applicable	No	Less
Florida	• Committee • Cancer registry IRB	No	Yes	<2	No	Yes	Yes	Not applicable	Not Applicable	Patient	No	Less
Hawaii	• Committee • Cancer registry IRB	No	Yes	<2	Yes	Yes	Yes	Patient	Not Applicable	Not applicable	No	More
Louisiana	• Committee • Cancer registry IRB	No	Yes	<2	No	Yes	Yes	Not applicable	Not Applicable	Patient	Yes	More
Massachusetts	• Committee • Commissioner	No	No	Varies	No	Yes	Yes	Patient	Not Applicable	Not applicable	No	Middle
Minnesota	• Cancer surveillance committee • Peer review committee	Yes	Yes	2–6	No	No	Yes	Physician and patient	Not Applicable	Not applicable	No	More
New Hampshire	• Committee • Cancer registry IRB	Yes	No	<2	No	No	Yes	Not applicable	Not Applicable	Physician	No	More
New Jersey	• Committee • Cancer registry IRB	No	Yes	Varies	No	Yes	Yes	Patient	Not Applicable	Not applicable	No	Middle
New Mexico	• Cancer registry director • Cancer registry IRB	No	Yes	Varies	Yes	Yes	Yes	Physician and patient	Physician and Patient	Not applicable	No	More
New York	• Committee • Cancer registry IRB	No	Yes	2–6	No	No	Yes	Physician and patient	Physician and Patient	Not applicable	No	Middle
North Carolina	• Committee • Committee	No	Yes	<2	No	No	Yes	Physician	Physician	Patient	No	Less
North Dakota	• Committee • Committee	No	No	2–6	No	No	Yes	Varies	Varies	Varies	No	Middle

State	Two levels of approval*	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Ohio	• Committee • Cancer registry IRB	No	No	2–6	No	No	Yes	Not applicable	Not Applicable	Physician	No	Middle
Rhode Island	• Cancer registry director • Cancer registry IRB	Yes	No	2–6	No	No	Yes	Not applicable	Not Applicable	Patient	No	More
South Carolina	• Committee • Cancer registry IRB	No	Yes	2–6	No	No	Yes	Physician and patient	Physician and Patient	Not applicable	No	Middle
Tennessee	• Committee • Cancer registry IRB	No	No	Varied	No	Yes	Yes	Patient	Not Applicable	Not applicable	Yes	More
Utah	• Committee • Cancer registry IRB	Yes	Yes	Varied	No	Yes	Yes	Patient	Not Applicable	Not applicable	No	More
Virginia	• Cancer registry IRB • Commissioner	No	No	<2	No	Yes	Yes	Varies	Varies	Varies	No	Less
Washington	• Cancer registry IRB • Assistant secretary	No	No	Varied	No	No	Yes	Patient	Not Applicable	Not applicable	No	Middle
West Virginia	• Cancer registry director • Committee	No	Yes	2–6	No	No	Yes	Varies	Varies	Varies	Yes	More
Wyoming	• Committee • Cancer registry IRB	Yes	No	<2	No	No	Yes	Varies	Varies	Varies	No	More

Cancer Registry Research Approval Process
Classification of States by Level of Approval Required

3. States that require three levels of approval

State	Three levels of approval*	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Alabama	• Cancer registry director • Committee • Cancer registry IRB	Yes	Yes	Varies	No	No	Yes	Physician	Physician	Not applicable	Yes	More
Delaware	• Epidemiologist • Committee • Cancer registry IRB	No	No	2–6	No	No	Yes	Not applicable	Not Applicable	Patient	No	Middle
Iowa	• Epidemiologist • Cancer registry IRB • Committee	Yes	Yes	<2	No	Yes	Yes	Patient	Not Applicable	Not applicable	No	Less
Maine	• Cancer registry director • Committee • Cancer registry IRB	Yes	Yes	2–6	No	No	Yes	Not applicable	Not Applicable	Physician	No	More
Michigan	• Cancer surveillance committee • Scientific committee • Department of health director	Yes	Yes	2–6	No	Yes	Yes	Physician and patient	Not Applicable	Not applicable	No	More
Missouri	• Committee • University of Missouri IRB • Cancer registry IRB	No	Yes	2–6	No	Yes	Yes	Patient	Not Applicable	Not applicable	Yes	More
Nebraska	• Cancer registry director • Committee • Administrator	No	Yes	<2	No	No	Yes	Patient	Not Applicable	Not applicable	No	Less
Nevada	• Cancer registry biostatistician • Cancer registry manager • Bureau chief	Yes	Yes	2–6	No	No	Yes	Varies	Varies	Varies	No	More

State	Three levels of approval*	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Oklahoma	• Cancer registry • Cancer registry IRB • Commissioner	No	No	Varies	No	Yes	Yes	Physician and patient	Not Applicable	Not applicable	No	Middle
Oregon	• Cancer registry director • Cancer registry IRB • Committee	Yes	Yes	2–6	No	No	Yes	Physician and patient	Physician and Patient	Not Applicable	No	More
Puerto Rico	• Cancer registry director and coordinator • Cancer registry IRB • Committee	Yes	No	2-6	No	Yes	Yes	Not applicable	Not Applicable	Physician	No	More
South Dakota	• Cancer registry director • Cancer registry committee • Executive committee	No	Yes	<2	No	No	Yes	Not applicable	Not Applicable	Physician	No	Less
United States Pacific Islands	<u>Specific Territory:</u> • Cancer registry director • Official/local IRB <u>Regional:</u> • Cancer registry director • Committee	No	No	2–6	No	No	Yes	Not applicable	Not Applicable	Physician	No	Middle
Vermont	• Cancer registry director • Committee • Cancer registry IRB	No	Yes	2–6	No	Yes	Yes	Physician and patient	Physician and Patient	Not Applicable	No	Middle

Cancer Registry Research Approval Process
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4. States that require four levels of approval

State	Four levels of approval*	Pediatric special require-ments	Fee	Timeframe (months)	Sponsorship required	Human subjects protection training required	Patient contact studies allowed	Physician/ patient authorization by cancer registry	Physician notification/ patient authorization by cancer registry	Physician/ patient authorization by researcher	Limit on number of studies	Level of complexity
Kansas	• Committee • Cancer registry IRB • Cancer registry IRB • Committee	No	Yes	Varies	Yes	Yes	Yes	Patient	Not Applicable	Not applicable	No	Middle
Maryland	• Cancer registry director • Cancer registry officials • Cancer registry IRB • Department of Health	No	No	Varies	No	No	Yes	Patient	Not Applicable	Not applicable	No	Middle
Montana	• Cancer registry committee • Bureau chief • Administrator • Legal counsel	No	Yes	<2	No	No	Yes	Not applicable	Not Applicable	Patient	No	Less
Texas	• Cancer registry director • Cancer registry IRB • Committee • Commissioner	Yes	No	<2	No	Yes	Yes	Not applicable	Not Applicable	Patient	No	More

Level of Complexity by State Cancer Registry

Less Complex Process	Middle Complex Process	More Complex Process
Arkansas	Arizona	Alaska
Florida	Connecticut	Alabama
Indiana	Delaware	California
Iowa	District of Columbia	Colorado
Kentucky	Kansas	Georgia
Mississippi	Maryland	Hawaii
Montana	Massachusetts	Idaho
Nebraska	New Jersey	Illinois
North Carolina	New York	Louisiana
Pennsylvania	North Dakota	Maine
South Dakota	Ohio	Michigan
Virginia	Oklahoma	Minnesota
	South Carolina	Missouri
	United States Pacific Islands	Nevada
	Vermont	New Hampshire
	Washington	New Mexico
		Oregon
		Puerto Rico
		Rhode Island
		Tennessee
		Texas
		Utah
		West Virginia
		Wisconsin
		Wyoming

Appendix: Classification and Analysis Tables
Cancer Registries Human Subject Protection Policies and Procedures

Classification Category Definitions

Classification Category	Definition
1. Initial cancer registry contact required prior to application submission	How to initiate the data request process: clarifies if the researcher should contact the cancer registry representative or the IRB as a first step in the process.
2. State cancer registry allows release of state residents' identifiable data to researchers	State cancer registry allows identifiable and confidential data to be released to researchers as long as the researcher meets all required state cancer registry-specific confidentiality requirements and obtains the necessary approvals.
3. Requirement of sponsorship from local researcher	Clarifies if sponsorship from a local epidemiologist or state-based researcher is required.
4. Requirement of cancer registry-specific human subject protection training	This section clarifies if the IRB of record or the cancer registry has specific human subject protection training requirements.
5. IRB approval from requested state and/or researcher's affiliated institution	Clarifies and identifies the number of IRBs that need to review and approve the research project.
6. Pediatric research special requirements	Clarifies if the state has special requirements for pediatric research.
7. Patient contact, authorization, and consent required for release of confidential data	State-specific requirements for contacting patients and obtaining consent for research purposes.
8. Detail and number of steps in the approval process	Identifies the number of regulatory bodies and process of review and approval required for research studies. Categories include one to four or more levels.
9. Frequency of IRB and other regulatory committee meetings	Categories include weekly, monthly, quarterly, bi-monthly, semi-monthly, other, and unknown.
10. Charge and structure of fee	Provides information regarding the cost of a data request.
11. Timeframe for the approval process	The length of time generally required for data request processes and research approvals.
12. Limit on number of studies	The number of active projects a researcher may have open with the cancer registry.
13. Involvement of cancer registry director or senior official in approval process	Clarifies if cancer registry administrators and senior officers are involved in the research review and approval process. In general, involvement of cancer registry officials is considered a positive feature.

Cancer Registry Data Access for Research Classification and Analysis Tables

1. Initial cancer registry contact required prior to application submission

No Initial Contact Required (7)	Initial Contact Required (46)
Alabama, Arkansas, California, Connecticut, Florida, Massachusetts, North Carolina, Virginia	Alaska, Arizona, Colorado, Delaware, District of Columbia, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming

2. State cancer registry allows release of state resident's identifiable data to researchers

Does Not Allow Release (0)	Allows Release (53)
None	Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, North Carolina, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin,* Wyoming

*Wisconsin allows access to identifiable data under very strict circumstances.

3. Requirement of sponsorship from local researcher

No Sponsorship Required (50)	Sponsorship Required (3)
Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Idaho, Illinois, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri,* Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, Wisconsin, West Virginia, Wyoming	Georgia, Hawaii, Kansas, New Mexico

*Missouri Department of Health and Senior Services IRB requires sponsorship by a local researcher, but the IRB of record (the University of Missouri IRB) does not.

4. Requires cancer registry specific human subject protection training

No Specific Human Subject Protection Training Required (34)	Specific Human Subject Protection Training Required (19)
Alabama, Alaska, Arizona, Arkansas, California, Delaware, District of Columbia, Georgia, Idaho, Illinois, Indiana, Kentucky, Maine, Maryland, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New York, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, U.S. Pacific Islands, Washington, West Virginia, Wisconsin, Wyoming	Colorado, Connecticut, Florida, Hawaii, Iowa, Kansas, Louisiana, Massachusetts, Michigan, Missouri, New Jersey, New Mexico, Oklahoma, Puerto Rico, Tennessee, Texas, Utah, Vermont, Virginia

5. Requires IRB approval from requested state and/or researcher's affiliated institution

IRB Approval State-Specific Requirement	Total	States
IRB approvals from both researcher's and registry-affiliated institution	30	Alabama, California, Connecticut, Delaware, District of Columbia, Florida, Illinois, Iowa, Kansas, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, New Hampshire, New Jersey, New Mexico, New York, Ohio, Oklahoma, Oregon, Puerto Rico, South Carolina, Tennessee, U.S. Pacific Islands, Utah,* Vermont, Virginia, Washington
Only IRB approval from researcher-affiliated institution	16	Alaska, Arkansas, Idaho, Indiana, Kentucky, Minnesota, Mississippi, Montana, Nebraska, Nevada, North Carolina, North Dakota, Pennsylvania, South Dakota, West Virginia, Wisconsin
Only IRB approval from registry-affiliated institution	5	Arizona, Georgia, Rhode Island, Texas, Wyoming
IRB approval from registry-affiliated institution but information not available if IRB approval required from researcher-affiliated institution	2	Colorado, Hawaii

*Utah requires approval from both researcher's and registry-affiliated institution or only from researcher's affiliated institution.

6. Pediatric research special requirements

Pediatric Special Requirements (16)	No Pediatric Special Requirements (37)
Alabama, Alaska, California, Idaho, Iowa, Maine, Michigan, Minnesota, Nevada, New Hampshire, Oregon, Puerto Rico, Rhode Island, Texas, Utah, Wyoming	Arizona, Arkansas, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Mississippi, Missouri, Montana, Nebraska, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, U.S. Pacific Islands, Vermont, Virginia, Washington, West Virginia, Wisconsin

Five states require parental and/or physician consent: Alabama, Iowa, Nevada, Rhode Island, Utah.

Seven states have a more difficult approval process or require more oversight: California, Maine, Michigan, Minnesota, Oregon, Utah, Wyoming.

Idaho requires a case-by-case review.

Texas does not provide parent contact information.

Four states have never handled pediatric study requests: Alaska, Hew Hampshire, Puerto Rico, Utah.

7. Patient contact, authorization and consent required for release of confidential data

7a. Cancer Registry Request Authorization from Physician and/or Patient

State Specific Requirement for Requesting Authorization	Total	States
Patient Authorization Required	15	Arkansas, Hawaii, Iowa, Illinois, Kansas, Kentucky, Massachusetts, Maryland, Missouri, Mississippi, Nebraska, New Jersey, Tennessee, Utah, Washington
Both Physician Notification and Patient Authorization Required (Passive Physician Consent)	7	Georgia, Idaho, New Mexico, New York, Oregon, South Carolina, Vermont
Both Physician and Patient Authorization Required (Active Physician Consent)	3	Michigan, Minnesota, Oklahoma
Physician Notification Required (Passive Consent)	3	Alabama, Colorado, North Carolina
Physician Authorization Required (Active Consent)	1	Alabama (pediatric)

Notes: Authorization may be waived by the IRB for the following state: Washington.

Active physician consent required for pediatric studies: Alabama

Registry must obtain passive physician consent when research study is within one year of participant diagnosis: North Carolina

7b. Researcher Requests Authorization from Physician and/or Patient

State Specific Requirement for Requesting Authorization	Total	States
Physician Authorization Required (Active Consent)	7	Connecticut, Maine, New Hampshire, Ohio, Puerto Rico, South Dakota, U.S. Pacific Islands
Physician Authorization Required (Passive Consent)	3	Arizona, Indiana, Louisiana
Patient Authorization Required	8	California, Delaware, Florida, Montana, North Carolina, Pennsylvania, Rhode Island, Texas

7c. Who consents patient for participation in the study?

State Specific Requirement for Consenting Patients	Total	States
Researcher contacts and consents	40	Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Texas, U.S. Pacific Islands, Utah, Vermont
Cancer registry contacts and consents	1	Hawaii
Options on consent	7	District of Columbia, Maryland, North Dakota, New Jersey, Virginia, Washington, Wyoming
No patient contact	2	Alaska, Wisconsin
Patient must contact researcher	1	Tennessee

State Specific Requirement for Consenting Patients	Total	States
Strict conditions for patient contact studies	2	Nevada, West Virginia

Notes: The following four states require the researcher to have prior informed consent from patient: Delaware, Montana, Nevada, West Virginia.
The following state's policy is under development; available spring 2012: Wisconsin.
The following state requires the researcher to send courtesy note to physician: Texas.

8. Detail and number of steps in the approval process

8a. One level of approval

State (14)	Summary of Level of Approval
Alaska	Alaska Cancer Registry Internal Review Committee
Arizona	Arizona Department of Health Services and Human Subjects Review Board IRB
California	Committee for Protection of Human Subjects IRB
Colorado	Colorado Department of Public Health and Environment IRB
Connecticut	Connecticut Department of Public Health Human Investigations Committee IRB
District of Columbia	District of Columbia IRB for the Public Health
Georgia	Georgia Department of Community Health IRB
Idaho	Idaho Cancer Analysis Work Group
Illinois	Illinois Department of Public Health IRB
Indiana	Indiana Cancer Registry Data Review Committee
Kentucky	Kentucky Cancer Registry Scientific Advisory Committee
Mississippi	Mississippi Cancer Registry Review Committee
Pennsylvania	Bureau of Health Statistics and Research
Wisconsin	Confidential data release policy under development. Currently, Wisconsin Cancer Registry for Data Linkage only

8b. Two levels of approval (up to two levels of approval depending on the research)

State (21)	Summary of Levels of Approval
Arkansas	• Chief Epidemiologist • Scientific Advisory Committee
Florida	• Florida Department of Health IRB • Florida Cancer Registry Program Bureau of Epidemiology
Hawaii	• University of Hawaii Committee on Human Studies IRB • Commission on Cancer of the Hawaii Medical Association IRB
Louisiana	• Louisiana State University Health Sciences Center IRB • Institutional Bio-Safety Committee
Massachusetts	• Research and Data Access Committee • Department of Health Commissioner (*If the researcher is part of or collaborating with the Massachusetts Department of Health, then the Massachusetts Department of Public Health Human Research Committee IRB is required in lieu of Research and Data Access Committee)
Minnesota	• Minnesota Cancer Surveillance System Administrative Review Group • Peer Review Committee
New Hampshire	• Health Statistics and Data Management Data Review Committee • New Hampshire Department of Health and Human Services IRB
New Jersey	• Scientific Review Board of the Cancer Institute of New Jersey • University of Medicine and Dentistry of New Jersey IRB
New Mexico	• New Mexico Cancer Registry Principal Investigator • Human Research Review Committee
New York	• New York State Department of Health Administrative Approval • New York State Department of Health IRB
North Carolina	• North Carolina Department of Health, State Center of Health Statistics • North Carolina Department of Health, State Cancer Advisory Board
North Dakota	• North Dakota Department of Health HIPAA Privacy Office • North Dakota Department of Health Privacy Board
Ohio	• Ohio Cancer Incidence Surveillance System • Ohio Department of Health IRB
Rhode Island	• Rhode Island Cancer Registry Program Director • Rhode Island Department of Health IRB
South Carolina	• Cancer Control Advisory Surveillance Subcommittee • South Carolina Department of Health and Environmental Control IRB
Tennessee	• Tennessee Department of Health IRB • Cancer Registry Data Use Committee
Utah	• University of Utah IRB • Utah Cancer Registry Advisory Research Committee
Virginia	• Virginia Department of Health IRB • Virginia Department of Health Commissioner of Public Health
Washington	• Washington State IRB • Washington State Department of Health Assistant Secretary
West Virginia	• West Virginia Cancer Registry Director and West Virginia State Epidemiologist • Cancer Advisory Committee
Wyoming	• State Epidemiologist • Wyoming Department of Health IRB

8c. Three levels of approval (up to three levels of approval depending on the research)

State (14)	Summary of Levels of Approval
Alabama	• Alabama Statewide Cancer Registry Assistant Director • Alabama Statewide Cancer Registry Advisory Committee • Alabama Department of Health IRB
Delaware	• Chronic Disease Epidemiologist • Delaware Division of Public Health Privacy Board • Delaware Human Subjects Review Board
Iowa	• Iowa Cancer Registry Epidemiologist • University of Iowa IRB • Iowa Department of Public Health
Maine	• Maine Cancer Registry Director • Maine Cancer Registry Subcommittee • Maine Center for Disease Control and Prevention, Department of Health and Human Services, IRB
Michigan	• Michigan Cancer Surveillance Program • Scientific Advisory Panel • Director of Department of Community Health
Missouri	• Missouri Cancer Registry and Research Center Review Committee • University of Missouri Health Sciences IRB • Missouri Department of Health and Senior Services IRB
Nebraska	• Nebraska Cancer Registry Program Director • Department of Health and Human Services Public Health Support Unit Administrator • Department of Health and Human Services Legal Department
Nevada	• Nevada Cancer Registry Chief Biostatistician • Nevada Cancer Registry Program Manager • Chief of the Bureau of Health Statistics, Planning and Emergency Response
Oklahoma	• Oklahoma Central Cancer Registry • Oklahoma State Department of Health IRB • Commissioner of Health
Oregon	• Oregon Department of Human Services, Public Health IRB • Oregon State Cancer Registry Program Director • Oregon State Cancer Registry Advisory Committee
Puerto Rico	• Puerto Rico Cancer Registry Program Director and the Coordinator of Analysis and Research Unit • University of Puerto Rico Medical Sciences Campus IRB • Puerto Rico Cancer Registry Advisory Committee
South Dakota	• South Dakota Cancer Registry Program Director • A Committee of the South Dakota Cancer Registry • Executive Management (Secretary of Health and three Division Directors)
U.S. Pacific Islands	• If specific territory, up to three senior-level officials: ▪ Pacific Regional Central Cancer Registry (PRCCR) Program Director ▪ Senior level ranking official ▪ Local IRB • If regional level, two senior-level officials: ▪ Pacific Regional Central Cancer Registry (PRCCR) Program Director ▪ Pacific Islands Health officers association
Vermont	• Vermont Cancer Registry Program Chief • Vermont Department of Health Legal Department • Vermont Agency of Human Services IRB

8d. Four or more levels of approval (up to four levels of approval depending on the research)

State (4)	Summary of Level of Approvals
Kansas	• Kansas Cancer Registry Data Release Board • University of Kansas Medical Center (KUMC) IRB or KUMC and Kansas Department of Health and Environment IRB • Department of Health Secretary's Advisory Committee on Human Research Protection
Maryland	• Maryland Cancer Registry Program Director • Two senior level Department of Health and Mental Hygiene officials • Department of Health and Mental Hygiene IRB • Secretary of the Department of Health and Mental Hygiene
Montana	• Montana Central Tumor Registry Data Use Review Committee • Chief of Chronic Disease Prevention and Health Promotion Bureau • Administrator of the Public Health and Safety Division • Legal Counsel of the Department of Public Health and Human Services
Texas	• Texas Cancer Registry Director • Texas Department of State Health Services (DSHS) IRB • Texas Department of State Health Services Executive Oversight Committee • Texas Department of State Health Services Commissioner

9. Frequency of IRB and other regulatory committee meetings

Summary of Frequency	Total	States
Weekly	3	Indiana, Iowa, New Mexico
Monthly	11	Connecticut, District of Columbia, Hawaii, New Hampshire, Ohio, Oklahoma, Oregon, Tennessee, Texas, Vermont, Washington, Wyoming
Quarterly	6	Colorado, Kansas, Maine, South Carolina, Virginia, West Virginia
Bimonthly	3	California, New York, Missouri
Semimonthly	1	Puerto Rico
As needed	2	Idaho
5–6 per month	1	Utah
Unknown	27	Alabama, Alaska, Arizona, Arkansas, Delaware, Florida, Georgia, Illinois, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Pennsylvania, Rhode Island, South Dakota, U.S. Pacific Islands, Utah, Wisconsin

10. Charges a fee

No Fee (22)	Charge of Fee (31)
Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, District of Columbia, Indiana, Maryland, Massachusetts, New Hampshire, North Dakota, Ohio, Oklahoma, Puerto Rico, Rhode Island, Tennessee, Texas, U.S. Pacific Islands, Virginia, Washington, Wyoming	Alabama, California, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, Oregon, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, West Virginia, Wisconsin

11. Timeframe for the approval process

Summary of Timeframe	Total	States
<2 months	22	Arkansas, California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Idaho, Indiana, Iowa, Kentucky, Louisiana, Mississippi, Montana, Nebraska, New Hampshire, North Carolina, Pennsylvania, South Dakota, Texas, Virginia, Wyoming
2–6 months	18	Colorado, Delaware, Maine, Michigan, Minnesota, Missouri, Nevada, New York, North Dakota, Ohio, Oregon, Puerto Rico, Rhode Island, South Carolina, U.S. Pacific Islands, Vermont, West Virginia
Varies	13	Alabama: Complexity of the research, patient contact study Alaska: Timeframe unknown, never processed request for access to identifiable data Arizona: Complexity of the research, patient contact study Illinois: Complexity of the research Kansas: Complexity of the research, type of research, type of data requested Massachusetts: Complexity of research, completeness of application, and MCR priorities Maryland: Project needs, cancer registry priorities, IRB schedule New Jersey: Complexity of the research and staffing New Mexico: Complexity of the research Oklahoma: Complexity of the research, type of study, and type of data requested Tennessee: Timeframe unknown, approval process changing, previous requests took 6 months Utah: Depends on the project; complex projects require legal review and takes longer Washington: Complexity of the research Wisconsin: Time of year, other priorities, staffing, typically 1 week to 3–4 months

12. Limit on number of studies

Do Not Limit Studies (48)	Limit Studies (5)
Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Montana, , Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, South Dakota, Texas, U.S. Pacific Islands, Utah, Vermont, Virginia, Washington, Wisconsin, Wyoming	Alabama, Louisiana, Missouri, Tennessee, West Virginia

Alabama: Registry allows five active projects at one time due to staff shortages; IRB-approved study placed in queue.

Louisiana: Registry limits number of contact studies per patient to minimize patient burden. No patient can be contacted by more than one study regardless of researcher.

Missouri: Registry limits studies by restricting cases from the same population and same time period.

Tennessee: IRB has limited administrative capabilities, limit on number of studies they manage at one time.

West Virginia: Registry must limit the number of studies managed at one time due to limited staff available.

13. Involvement of cancer registry director or senior official in approval process

No Involvement in Approval Process (6)	Involvement in Approval Process (47)
Connecticut, Massachusetts, New Hampshire, New York, Pennsylvania, Virginia	Alabama, Alaska, Arizona, Arkansas, California, Colorado, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, U.S. Pacific Islands, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming